Living with chronic or persistent UTI symptoms

UTI INFORMATION SERVICE

THE UROLOGY FOUNDATION

Living with chronic or persistent UTI symptoms

If you are living with ongoing UTI symptoms that don't fully go away, this guide is for you. Many people tell us:

- ***"My symptoms never completely settle"***
- ***"Antibiotics help a bit, then the symptoms come back"***
- ***"My urine tests are negative but I still feel like I have a UTI"***
- ***"I feel worn down and not listened to"***

Persistent urinary symptoms can be distressing, exhausting, and isolating. Support and options are available, even when answers are not straightforward.

What do we mean by chronic or persistent UTI symptoms?

Some people describe a clear starting point for their symptoms. For example, a bladder or kidney infection that never fully settled, or symptoms that began after a particular trigger such as sex, hormonal changes, illness or a period of stress.

For others, symptoms develop more gradually over time.

Understanding your own pattern can be an important part of finding the right support, including any triggers or changes around the time symptoms began.

In research and specialist settings, chronic UTI may be discussed as persistent infection, chronic bacterial cystitis, or ongoing bladder inflammation; terms that reflect different theories rather than a single agreed diagnosis. Finding an agreed definition is a current research priority.[1]

Some people experience ongoing UTI symptoms that last for weeks or months, or that flare repeatedly without full relief in between.

This is different from *recurrent UTIs,* where infections clear completely with treatment and people feel well again between episodes.

You may recognise yourself here if:

- Symptoms are present most days, or
- Symptoms improve but never fully resolve, or
- Symptoms return very quickly after treatment, or
- Tests are often reported as "negative" despite ongoing discomfort

The term *chronic UTI* is not always used consistently in medicine, but persistent symptoms deserve explanation, investigation and support, whatever label is used.

Over recent years, more people living with persistent UTI symptoms have begun sharing their experiences. Some describe feeling unsure or concerned when tests are negative, or when their symptoms don't fit neatly into standard definitions.

There is increasing awareness that current testing methods do not provide all the answers for every individual. Improving diagnosis and understanding of long-term UTI symptoms is recognised as an important area for ongoing research and collaboration between patients and healthcare professionals.

While terminology may vary and research continues to evolve, what remains clear is this: ongoing UTI symptoms are real, can be very distressing, and deserve thoughtful assessment and supportive care.

Symptoms may include:

Urinary symptoms

- Burning, stinging or discomfort when passing urine
- Needing to pass urine more often than usual
- A sudden urge to urinate that is difficult to control
- Getting up at night to urinate (nocturia)
- Bladder pressure or a feeling of fullness
- Difficulty emptying the bladder completely
- Passing only small amounts of urine
- Urinary leakage or worsening of existing incontinence
- Symptoms that improve with treatment but then return

Pain and discomfort:

- Bladder pain or tenderness
- Pelvic pain or pressure
- Lower abdominal pain
- Pain or discomfort in the groin
- Pain, pressure or discomfort in the area between the genitals and back passage (the perineum)
- Lower back pain
- Pain in the sides of the back (flank pain)
- Pain that may radiate into the upper thighs

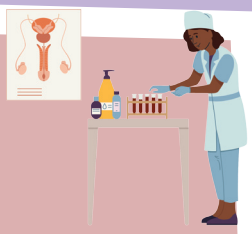
Additional symptoms some people report:

- Feeling generally unwell or fatigued
- Difficulty concentrating or *"brain fog"*
- Symptoms that flare after sex
- Symptoms triggered by certain foods, drinks or activities
- Symptoms that fluctuate over time

Men may also experience:

- Discomfort in the penis or testicles
- Pain during or after ejaculation
- Rectal pain

Why tests don't always give clear answers



Standard urine dipsticks and cultures are designed to detect *common, fast-growing bacteria.* They work well for many people, but not for everyone.

Possible reasons tests may be negative despite symptoms include:

- Low levels of bacteria that fall below test thresholds
- Intermittent shedding of bacteria
- Some bacteria are more difficult to grow using standard tests
- Recent antibiotics suppressing bacterial growth

For some people, symptoms may persist due to ongoing inflammation or sensitised bladder nerves, even when bacteria are not easily detected.

Importantly:

Your symptoms matter, not just the test results.

Both are important when making decisions about care.

Looking a bit deeper

Standard cultures are designed to detect bacteria above a certain threshold (often ≥10^5 CFU/mL). Research suggests symptoms can occur at much lower bacterial counts, or when bacteria are intermittently released from the bladder lining.

Getting the best possible urine sample

If you are asked to provide a urine sample, how it is collected can affect the result.

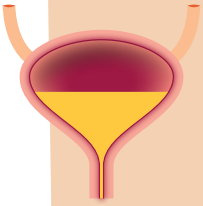
To reduce the chance of contamination and improve accuracy:

- Wash your hands before collecting the sample
- Use a clean container
- Take a midstream sample (start passing urine, then collect part-way through)
- Avoid touching the inside of the container
- If possible, get the sample to the clinic promptly

Ask about special urine collection devices, which help you to save a more accurate sample.

Even when collected carefully, tests do not always tell the full story but a good sample gives the best chance of a reliable result.

If you are unsure, your GP practice or nurse can guide you. You can also download our guides with information on how to collect a urine sample.[2,3]



Embedded infection and bladder inflammation

Research suggests that in some cases, bacteria may persist within the bladder lining or form protective communities (sometimes called biofilms).

Biofilms are an area of active research. While they help explain why symptoms may persist for some people, they are not yet routinely identified or specifically targeted in standard NHS testing.

This may:

- Trigger repeated symptoms
- Lead to partial or temporary improvement with antibiotics
- Cause flares rather than clear-cut infections

At the same time, repeated infection and inflammation can make the bladder more sensitive, meaning symptoms may continue even after bacteria are reduced.

This does not mean symptoms are imagined. It means the bladder may need time, *protection and support* to recover.

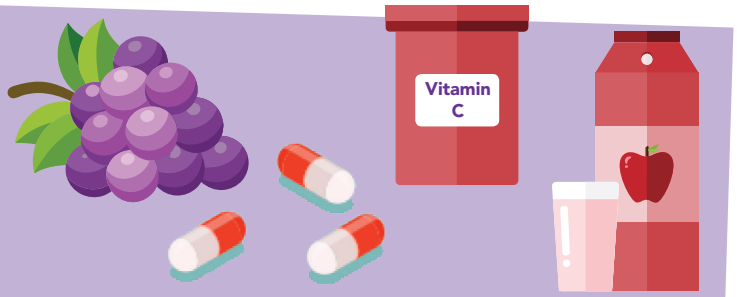
Chronic UTI and other overlapping conditions

Persistent UTI symptoms can overlap with other conditions, including:

- Bladder pain syndrome / interstitial cystitis
- Vaginal atrophy (especially during peri- or post-menopause)
- Pelvic floor muscle dysfunction
- Overactive bladder
- Endometriosis

These conditions can co-exist. Having one does not rule out another.

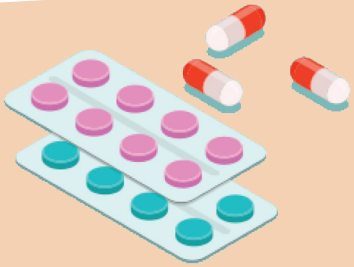
A careful, open-minded approach is essential.



Managing chronic UTI symptoms

For many people, improvement comes from combining several approaches rather than relying on one single treatment alone.

Why antibiotics may help - but not solve everything



Antibiotics can be helpful for some people with persistent symptoms, particularly during flares. However:

- Short courses may not fully resolve symptoms
- Repeated use carries risks, including resistance and side effects
- Symptom relief does not always equal cure

Antibiotics are *one tool*, but not the only option.

In specialist care, some patients are supported with longer or tailored treatment plans, but this requires careful oversight to balance symptom relief with safety and resistance risk.

A balanced approach looks at symptom control, prevention, bladder health and overall wellbeing.

Medical options

These may include (depending on individual assessment):

- Carefully considered antibiotic strategies
- Methenamine hippurate (a non-antibiotic preventive option)
- Vaginal oestrogen (for those affected by hormone changes often leading to vaginal dryness)
- Pain relief to manage flares
- Bladder instillations

These treatments can be used in combination.

Always discuss options with your GP or specialist.

Supporting your bladder

- Aim for steady hydration (avoid extremes)
- Reduce bladder irritants during flares (caffeine, alcohol, fizzy drinks)
- Use gentle heat (hot water bottle or heat pad) for comfort
- Rest and pace activity during symptom flares

Nutrition and bladder comfort

Some people notice that certain foods or drinks make their symptoms worse, particularly during flares. Common triggers can include caffeine, alcohol, fizzy drinks and highly acidic foods but this varies a great deal from person to person.

Rather than making drastic changes, it can help to notice patterns and adjust gently.

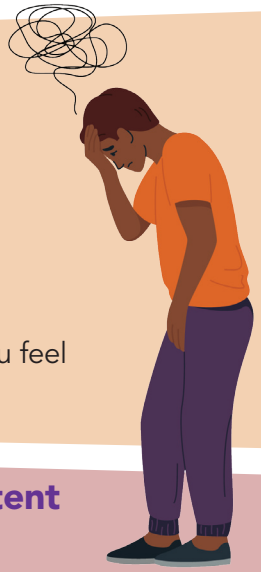
A balanced diet that supports overall health may also support bladder recovery. This includes:

- Drinking enough fluid to keep urine pale (but avoiding overhydration)
- Eating fibre-rich foods to support gut health
- Including anti-inflammatory foods such as oily fish, leafy greens, olive oil and nuts
- Considering fermented foods if well-tolerated

There is no single "UTI diet." The goal is comfort, balance and sustainability - not restriction.

For more information see The Urology Foundation's guide to nutrition and UTIs.[4]

Understanding flares



Flares can be triggered by:

- Stress or emotional strain
- Illness or fatigue
- Hormonal changes
- Sexual activity

Having a flare plan can help you feel more in control.

Living well with persistent symptoms

Living with chronic urinary symptoms can affect:

- Work and daily life
- Intimacy and relationships
- Confidence and mood

These impacts are real and valid.

Many people find that symptoms become more manageable over time with the right combination of medical care, practical strategies and the right support around them.

Try to be gentle with yourself. Improvement doesn't usually happen in a straight line, there may be better days and more difficult days along the way.

Talking to your GP or specialist

You may find it helpful to:

- Keep a symptom diary
- Note what helps and what worsens symptoms
- Bring questions written down

You might ask:

- "Could there be ongoing inflammation or sensitisation?"
- "Are non-antibiotic options suitable for me?"
- "Would vaginal oestrogen help?"
- "Can I be referred to a specialist or UTI clinic?"

You deserve to be listened to.

When to seek urgent help

Seek urgent medical advice if you develop:

- High fever or chills
- Severe back or side pain
- Vomiting
- Confusion or sudden deterioration

These may indicate a more serious infection and need prompt care.

Reasons for Hope

- Better understanding of persistent symptoms and embedded infection
- Improved testing and diagnosis
- Vaccines and immune-based treatments
- New antibiotics and bladder therapies
- Research into biofilm-disrupting treatments and technologies
- More personalised approaches to care
- Patients helping shape future research

While there are still unanswered questions, research in this field is growing rapidly and offers real hope for the future.

References

1. AMR Action UK. 2026. 'Chronic and recurrent urinary tract infection James Lind Alliance priority setting partnership: final report'. Available: https://www.jla.nihr.ac.uk/priority-setting-partnerships/chronic-and-recurrent-urinary-tract-infection-uti#tab-top-10-priorities (date accessed 14 April 2026). *This includes a list of agreed top ten research priorities in chronic and recurrent UTI.*
2. The Urology Foundation. 2025. 'How to collect a urine sample for a UTI Test' Available: https://www.theurologyfoundation.org/app/uploads/2025/07/How-to-collect-a-urine-specimen-for-a-UTI-Test.pdf (date accessed April 2026)
3. The Urology Foundation. 2025. 'How to collect a urine sample if you use a catheter'. Available: https://www.theurologyfoundation.org/app/uploads/2025/07/How-to-collect-a-urine-specimen-if-you-use-a-catheter.pdf (date accessed April 2026)
4. The Urology Foundation. 2026. 'Healthy eating for a happy bladder: Our guide to UTIs and nutrition' Available: https://www.theurologyfoundation.org/app/uploads/2026/03/UTI-and-Nutrition-Guide.pdf (date accessed: April 2026)

What is a UTI?

A Urinary Tract Infection (UTI) is a common infection that can affect anyone, regardless of age, and involves the urinary system but most commonly the bladder. UTIs are the second most common kind of infection after chest infections.

UTIs can be uncomfortable and debilitating. They can be particularly serious in the elderly and those with weakened immune systems. Early detection and proper management are essential to prevent complications.

What are the symptoms?

UTIs can cause a variety of symptoms, which may include:

- Burning sensation during urination
- Cloudy or strong-smelling urine
- Frequent urge to urinate with little or nothing being passed
- Fever or high temperature
- Feeling generally unwell
- Confusion in the elderly

These symptoms can vary in severity, and early detection is important to prevent complications, especially in vulnerable individuals. UTIs can progress to sepsis, a life-threatening condition. Watch for high fever, rapid breathing, and confusion.

Urgent help - If symptoms worsen quickly or you experience any severe symptoms mentioned above, immediate action is necessary: Call NHS 111 for guidance or to find out if you have severe symptoms and need urgent medical care.

For more detailed information on managing and treating UTIs, please refer to our specific treatment-focused information on our website:
https://www.theurologyfoundation.org/urology-health/bladder-conditions/urinary-tract-infections-uti/

For information on the references we have used and information on further reading please contact nurse@theurologyfoundation.org

Our confidential UTI Information Service is here to help you:

0808 801 1108 **Helpline open Tuesdays and Thursdays 10am - 12 noon**

nurse@theurologyfoundation.org

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THE UROLOGY FOUNDATION

www.theurologyfoundation.org

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